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## **WHAT DO WE MEAN BY 'DISABILITY' AND DO LABELS MATTER?**

**Sasha Scambler**

In 2011 the World Health Organisation published the first World Report on Disability. They estimated that more than 1 billion people across the world, approximately 15% of the population, live with a disability, and this number is likely to rise with the ageing population and the increasing number of people living with long-term disabling conditions. Alongside this, disabled people are increasingly portrayed in the British media as work-shy, scroungers or a burden.

Yet there remains no universally accepted understanding of the concept of disability. The nature, meaning and impact of disability depend on the geographical, historical, social, cultural and economic environment in which the person with the disability is located. In addition to being culturally specific the concept of disability is also historically specific and the treatment of people with disabilities has changed over time. Recognition and understanding of the various ways in which the term is used and the social implications of the definitions is increasingly important if we want to understand the social position of disabled people today. In this article we look at data and research on disability and disabled people and explore whether labels matter. There is much debate about language and throughout this article the term 'disabled people' is used as the preferred term of the disability movement.

### **The Profile of Disability in the UK**

1 in 10 people in the UK live with a disability – which equates to over 11 million disabled people (Family Resources Survey 2010/11). The prevalence of disability increases with age rising from 6% of children to 16% of working age adults and 45% of those over state pension age reporting a disability, and mobility problems are the most common reported impairments in GB. The evidence from the WHO suggests that disabled people experience poorer health outcomes, lower educational achievement, increased levels of dependency and restricted participation in society, have lower employment rates and are more likely to live in poverty than their non-disabled peers.

The position of disabled people in the UK has improved over the past decade and disabled people are more likely to be in employment now than they were in 2002 (Labour Force Survey 2012). This said, disabled people are still significantly less likely to be employed than their non-disabled peers, with 46.3% of working age disabled people in employment as compared to 76.4% of non-disabled working age people. Disabled people are also more likely to live in poverty, to struggle in school and further or higher education, to face discrimination and to face barriers accessing leisure facilities or being active in the community than their non-disabled peers. They are also more likely to live in inappropriate (non-decent) accommodation, significantly less likely to live in households with internet access, and significantly more likely to be victims of crime than their non-disabled peers.

And it is not just disabled people themselves who are affected. Families with a disabled member are also disproportionately more likely to live in poverty than those without. Almost 1 in 5 individuals living in families with at least one disabled family member live in relative income poverty and the situation is slightly worse for children where 21% of

children living in a family with at least one disabled member is living in poverty (Family Resources Survey 2010/11). This compares to 16% of children in families with no disabled members.

### **Disability Rights**

Against this backdrop there has been the emergence, over the last 4 decades, of the disability rights movement which has raised the profile of disability and disabled people. There has been the campaign for inclusive education and the introduction of the Disability Discrimination Act (DDA) in the UK and the more recent Equalities Act (2010) which requires business and services to make 'reasonable adjustments' to ensure that disabled people are enabled to access services. Alongside the rights and activist networks has emerged the academic discipline of Disability Studies which both provides empirical evidence on the social position of disabled people in contemporary society and theoretical frameworks for understanding the concept of disability itself.

### **Defining Disability**

The central debate concerning definitions of disability has been ongoing since the late 1970s with the major arguments surrounding the medical and social models of disability and their corresponding advantages and disadvantages as ways of understanding exactly what disability is and what it means to people living with disabilities. The importance of developing an adequate definition of disability was seminally highlighted by Mike Oliver (1990). Human beings give meaning to the objects that they encounter within the social world and orientate their behaviour accordingly. Thus, if disability is given a strongly negative meaning, then its onset will be experienced and treated as a tragedy and disabled people will be treated as tragic victims. Oliver suggests that official or bureaucratic definitions attached to disability also define who is and is not able to work, offering quasi-legitimate social status to people who are not able to work as opposed to people who choose not to work.

In order to claim disability as a positive state, the terms surrounding disabilities and their meanings need to be reclaimed and redefined in a positive way. The Equalities Act (2010) is part of this process. Alongside this a growing body of theoretical work has explored how disability and disabled people are (and should be) understood in relation to bodies, impairments, and wider society. The ongoing debate hinges on the extent to which disabled people are seen as tragic victims to be 'helped' (the medical model approach) or individuals who happen to have an impairment but have the same rights and needs as their non-disabled peers (the social model approach).

### **The Medical Model of Disability**

In 1981 the World Health Organisation adopted the 'International Classification of Impairment, Disability and Handicap' (ICIDH), which became the most commonly used definition of disability amongst medical practitioners and other professionals, including medical sociologists. ICIDH states that:

**Impairment** - an impairment is any loss or abnormality of psychological, physiological or anatomical structure or function.

**Disability** - a disability is a restriction or lack (resulting from an impairment) of ability to perform an activity in a manner or within the range considered normal for a human being.

**Handicap** - a handicap is a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex and social and cultural factors) for that individual. (WHO 1981)

Criticisms of the ICIDH include:

- Emphasis placed on the individual and not on society.
- Emphasis on the impairment as the cause of disability and handicap.
- The environment is seen as neutral and the onus is placed on the individual, with the use of medical aids, to fit in to the environment
- There is an underlying assumption that disabled people should be willing to adjust themselves to become more normal

### **The Social Model of Disability**

The social model of disability developed alongside the medical model, providing an alternative definitional framework for understanding disability. The clearest version of this definition of disability is as follows:

**Impairment** - lacking part or all of a limb, or having a defective limb, organ or mechanism of the body.

**Disability** - the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have an impairment (whether it is physical, sensory or intellectual) and thus excludes them from participation in the mainstream of social activities. (adapted from UPIAS, 1976)

This definition rejects the idea that the body, and any impairment it may have, has anything to do with an individual's experience of disablement. It was designed to politicise the disability movement's struggle and highlight systematic social oppression of disabled people.

Criticisms of the social model include:

- The body is removed from debates around disability
- This gifts the body to medicine unchallenged and medicine is seen as the enemy
- This model removes embodied experiences, such as pain, from the debate and devalues the experiences of disabled people with many forms of impairment

This has led to the development of an area of disability studies concerned primarily with the disabled body and the impairment debate.

### **The International Classification of Functioning**

Problems with the existing definitions of disability led the WHO to revise the ICIDH and in 2001 the 'International Classification of Functioning, Disability and Health' (ICF) was released as an international standard to measure health and disability. The ICF was

incorporated into the United Nations Convention on the Rights of Persons with Disabilities in 2006 (UN, 2006).

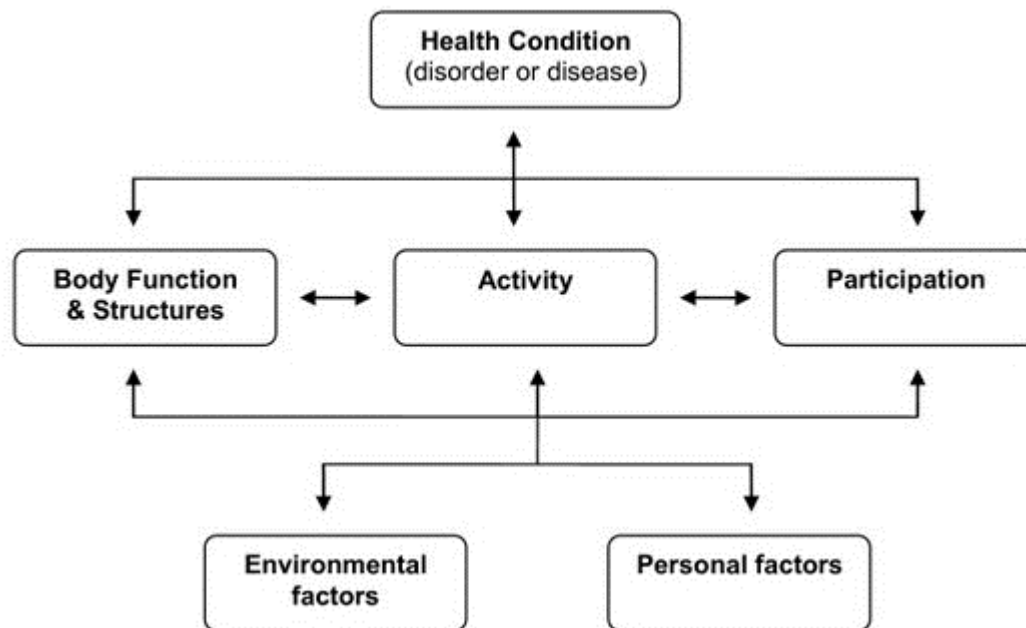


Figure 1: ICF Model  
(source: WHO 2001)

The three main elements of ICF (body functions, structures, activity) are designed to be co-participants in this new model of the aspects which, when combined, create the concept of disablement. It is important to note that they are designed to be seen as equal participants. Equally important is the assertion that ICF was designed as a health classification and cannot be seen as more than a way of classifying the consequences of health conditions. Proponents suggest that the ICF embodies a biopsychosocial approach to disability with each dimension conceptualised as interaction between the individual and their social and physical environment. The ICF is in wide use as a standard epidemiological tool in research across medicine and many allied fields.

It is no secret that the disability movement and many people within the disability field were unhappy from the outset, at the idea of revising the ICIDH, which they see as fatally flawed. The main criticism hinges on the role of bio-medicine in defining and 'treating' disability and the secondary role of society in shaping the experience of disability. It is this interface between the bio-medical and the social that is at the heart of the most recent debates around the introduction of a sociology of impairment as a way to bring the two aspects (biological and social) together.

### Changing Perceptions of Disability and Disabled People

One way in which the impact of the social environment on the disabled people who live and work within it can be seen is through changes in public perceptions and the presentation of disability and disabled people in the media.

Disability and disabled people regularly feature in the media with the most recent coverage focusing on welfare changes and the potential effect of benefit changes, eligibility tests and cuts on disabled people. Prior to this we had extensive coverage of the 2012 Paralympics which changed the narrative again. Prior to the 2012 Olympics the main focus of media stories was on impairment and difference, firmly in line with the medical model approach, and incorporating and promoting disability stereotypes. Disability activists and academics working in this field also suggest that the media campaigns put together by charities to raise money to help support disabled adults and children often do so through the portrayal of disabled people as 'tragic' and in need of care and help from the wider non-disabled population. Whilst this is a good strategy for increasing donations, it can have a detrimental effect on the way that disabled people are viewed by the general public.

If the changes in media stories are tracked in relation to the medical and social models of disability presented above we can see a move in public perceptions over the past 10 years. The traditional medical model image of disabled people as tragic victims in need of care and pity was replaced briefly (albeit in a very limited way) by a more positive focus on equality and the achievements of disabled athletes in the Paralympics. Whilst the 2012 London Olympics offered the opportunity for mainstream coverage of Paralympic sports, and created new heroes in disabled athletes such as David Weir, Hannah Cockcroft and Jonnie Peacock, much of the coverage focused on tragic victims overcoming all odds rather than on athletes training hard. This was then replaced by the current focus on disability which both reverts to the medical model approach in highlighting poor care and the impact welfare cuts but also introduces a new, and potentially even more dangerous shift to linking disabled people with unwillingness to work and benefit fraud.

Recent UK media coverage on the move from Disability Living Allowance to Personal Independence Payments, has been accompanied by some stories about people who have been re-assessed as 'fit for work' (and thus been denied benefits), dying within weeks of their re-assessments and even of disabled people committing suicide when forced to face the reality of living with no money. But alongside these stories are a raft of other pieces about benefit scroungers making fraudulent claims that cheat hardworking taxpayers. Carry out a search on the term 'disability' in a well-known tabloid newspaper and you find two pages of headlines on the benefits that are 'handed out to addicts and alcoholics', the 'breakdancers', 'traffic wardens' and 'holidaying conwomen' fraudulently claiming DLA, and the £1bn that could be reclaimed if the half of claimants who are fraudsters were forced back to work.

The DLA was originally intended to cover extra costs incurred by disabled people carrying out everyday tasks – hence could be seen as a legitimisation of need. The subversion of this promotes the view of people on Disability Living Allowance as benefits scroungers who should be out looking for work. And yet figures derived from spot checks carried out by the Department for Work and Pensions suggests that only 0.5% of DLA claims are fraudulent and that more people are actually underpaid than overpaid.

This shift in focus of the way in which disability and disabled people are viewed has real consequences particularly in relation to rising levels of hate crime against disabled people. Statistics presented by Tom Shakespeare at the UK Disability Studies Conference in 2012 suggest that disabled adults are 50% more likely to be victims of crime than non-disabled adults. Adults with mental health issues are 4 times more likely to be victims of violent crime 10 times more likely to be victims of hate crime than their non-disabled peers. Furthermore, disabled children are 57% more likely to be bullied and children with learning difficulties are 4 times more likely to be bullied or abused. Not only are disabled people more likely to be victims of hate crime than non-disabled people, the numbers of hate crimes reported over the past four years are going up.

The rise in hate crime reflects the importance of perceptions and the way that definitions, thinking and language shape the way people are viewed and treated in and by society.

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